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ABSTRACT

This technical report is part of a series on AIDS/HIV (Acquired Immune Deficiency Syndrome/Human Immunodeficiency Virus) and is intended to help link various legal advocacy organizations providing services to persons with mental illness or developmental disabilities. This paper examines AIDS policy issues in mental health institutions. The paper provides a discussion and specific recommendations for policy development for the following areas: (1) education; (2) HIV testing; (3) confidentiality; (4) duty to protect; (5) liability; and (6) access to services. Also included is a summary of interviews with four administrators at Washington D.C. institutions which demonstrate the daily issues confronting institutions. Includes 15 references. (DB)

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HIV & Mental Health Institutions

David C. Harvey, M.S.W.

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National Association of Protection & Advocacy Systems

The National Association of Protection & Advocacy Systems is the membership organization of 86 Protection & Advocacy Systems (P&As) and Client Assistance Programs (CAPs) located in every State and U.S. territory. P&A agencies for persons with developmental disabilities (PADD) were created by Congress as part of the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 94-103). In 1986, Congress added the Protection & Advocacy System for Mentally Ill Individuals (PAMI) (P.L. 99-319). The Client Assistance Program was created under Section 112 of the Rehabilitation Act of 1973 (P.L. 93-12).

P&As and CAPs are mandated to provide advocacy services through legal, administrative, and other appropriate remedies to protect the rights of persons with disabilities who reside in institutions, facilities, and other locations, and persons being served by state departments of vocational rehabilitation.

P&As and CAPs are increasingly confronting legal, policy and advocacy issues involving adults and infants infected with HIV, and a range of other issues associated with communicable disease policy, sexuality of persons with disabilities, and persons with dual diagnosis of mental illness or developmental disability and drug use. It is the hope of NAPAS that this series of technical reports will assist the field in responding to the newest challenge facing disability services.

Elizabeth J. Bauer, President, NAPAS (1990)
Executive Director, Michigan Protection & Advocacy Service, Inc.

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Purpose of Publication

In 1988, NAPAS submitted a grant proposal to the AIDS Prevention & Service Program of the Robert Wood Johnson Foundation, Princeton, New Jersey, to develop AIDS legal advocacy services through technical assistance to NAPAS members and production of monographs and research articles. NAPAS was awarded a grant January 1, 1989 for one year, together with 54 other grant recipients nationwide.

Published in April of 1990, this publication is the fourth in a series of technical reports on AIDS/HIV legal, policy and advocacy issues pertaining to mental health and developmental disability services. These technical reports are intended for wider distribution beyond Protection & Advocacy Systems and Client Assistance Programs to the disability and AIDS community, and are designed to help link various legal advocacy organizations in mutually beneficial and cooperative ventures. Although the responses and capabilities of agencies vary throughout the United States, these technical reports may provide assistance to others and can serve as guideposts for other organizations seeking to initiate or enhance similar efforts.

Comments and feedback on the usefulness of this technical report are welcome and should be addressed to David C. Harvey, Project Director, NAPAS, 220 Eye Street, NE, Suite 150, Washington, D.C. 20002, (202) 546-8202.

This technical report was researched and written by NAPAS staff member David C. Harvey, M.S.W., who is the Project Director of the Robert Wood Johnson Foundation AIDS grant. The author wishes to thank the NAPAS AIDS Advisory Committee for assisting with the conception of this paper and review of initial drafts.

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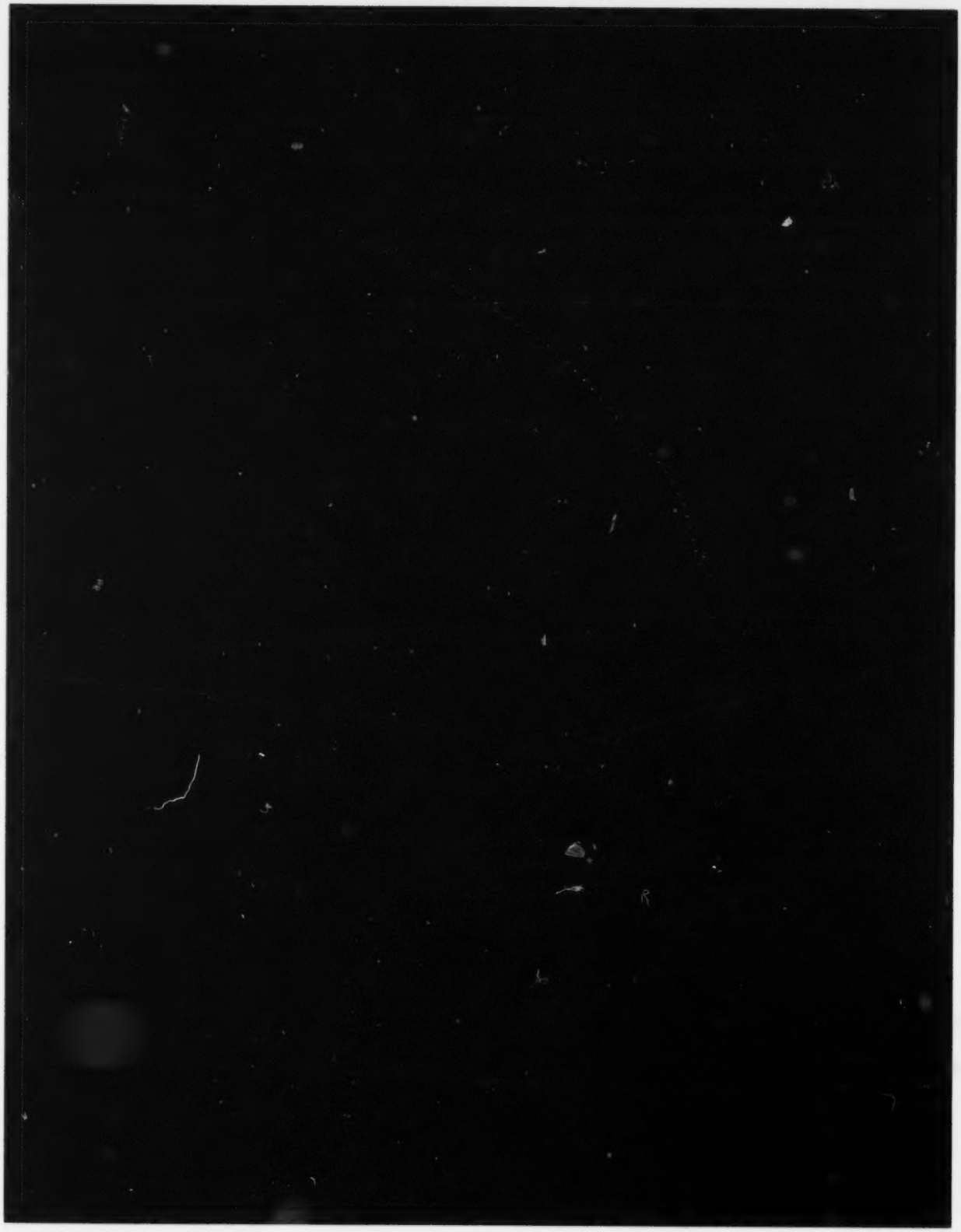

HIV & Mental Health Institutions

David C. Harvey, M.S.W.

Currently, there are no scientifically based, epidemiological studies completed of HIV infection among persons with pre-existing mental illness. However, one AIDS policy study (Harvey & Elliott, 1990), found that of 85 state and county mental hospitals from 37 states responding to a questionnaire, most report some in-patients with HIV infection. Although not an epidemiological study, staff who responded to this survey reported that these patients raise difficult patient management issues, and that the Centers for Disease Control (CDC) guidelines on prevention of HIV in hospitals does not address the circumstances of sexual and violent behavior that can happen in state mental facilities.

The Research Foundation for Mental Hygiene in New York City, is conducting a study that will estimate the rate of HIV infection in two state mental hospitals in New York, and assess the extent of risk-taking behavior of 200 patients through interviews in two hospitals and a homeless unit. Results are expected later this year.

While there is a lack of reliable data on the numbers infected in state mental institutions, policy concerns regarding HIV infection in mental health institutions have focused on some of the following issues:

- Education
- HIV testing
- Confidentiality
- Duty to Protect
- Liability
- Access to Services

This paper introduces discussion of each of these topic areas and cites specific recommendations for policy development.

Education

Past Surgeon General C. Everett Koop has stated that minus a cure or vaccine, education is the best primary means we have to combat the spread of HIV infection. Education must extend to mental health institutions and patients.

Psychiatric research and literature journals have begun to deal in-depth with mental illness caused by HIV infection, as well as presentations of HIV in state mental facilities (Horwath, 1989). Mental health services will be increasingly challenged to distinguish the cause of mental illness as resulting from HIV infection or organic syndromes. This sophistication will only occur after regular education is instituted for staff. In addition, some institutions report concerns in light of HIV regarding infection control prevention, patient milieus, and other issues (Houston-Hamilton, Day & Purnell, 1989).

In addition, as a means of providing primary and secondary education of patients to prevent transmission of HIV, and to advise those already infected on services and other issues, education programs for patients must be instituted. Not surprisingly, little attention has been given to prevention efforts with persons diagnosed with mental illness. Service systems for these populations have traditionally paid little attention to disease prevention activities. The newest challenge facing advocates is to insure that these systems respond to the newest health threat of AIDS, as well as other disease prevention issues among this population.

People with mental illness are at risk for exposure to HIV because they may engage in unknowing high-risk sexual behavior. This can include same-sex behavior in sex segregated facilities or unprotected vaginal or anal intercourse. Other vulnerability factors include victimization through high rates of sexual abuse suffered in facilities or on the streets (NAPAS, 1989), or use of drugs as a way of self-medicating symptoms of mental illness. In these situations, use of IV drugs or sexual abuse where exchange of blood or semen occurs, may transmit HIV. In addition, adolescents with emotional problems or mental illness are at particular risk for exposure because of the high rates of sexual and drug experimentation among this age group. Studies show that adolescents are among the fastest growing population of newly infected persons.

Myths concerning health education of people with disabilities are common. Most notable is the belief that people with mental illness or developmental disability are unable to cognitively integrate health promotion behaviors. The experience of educators and care-providers of this population suggest otherwise.

Advocates must work to create health prevention and maintenance programs with mental health services. Advocates should consult and work with AIDS service organizations in creating HIV education programs; conduct a needs assessment of the disability community; design programs that take into account staff and agency needs; and conduct creative strategies to form programs that may include using the press, politicians, service providers, and others.

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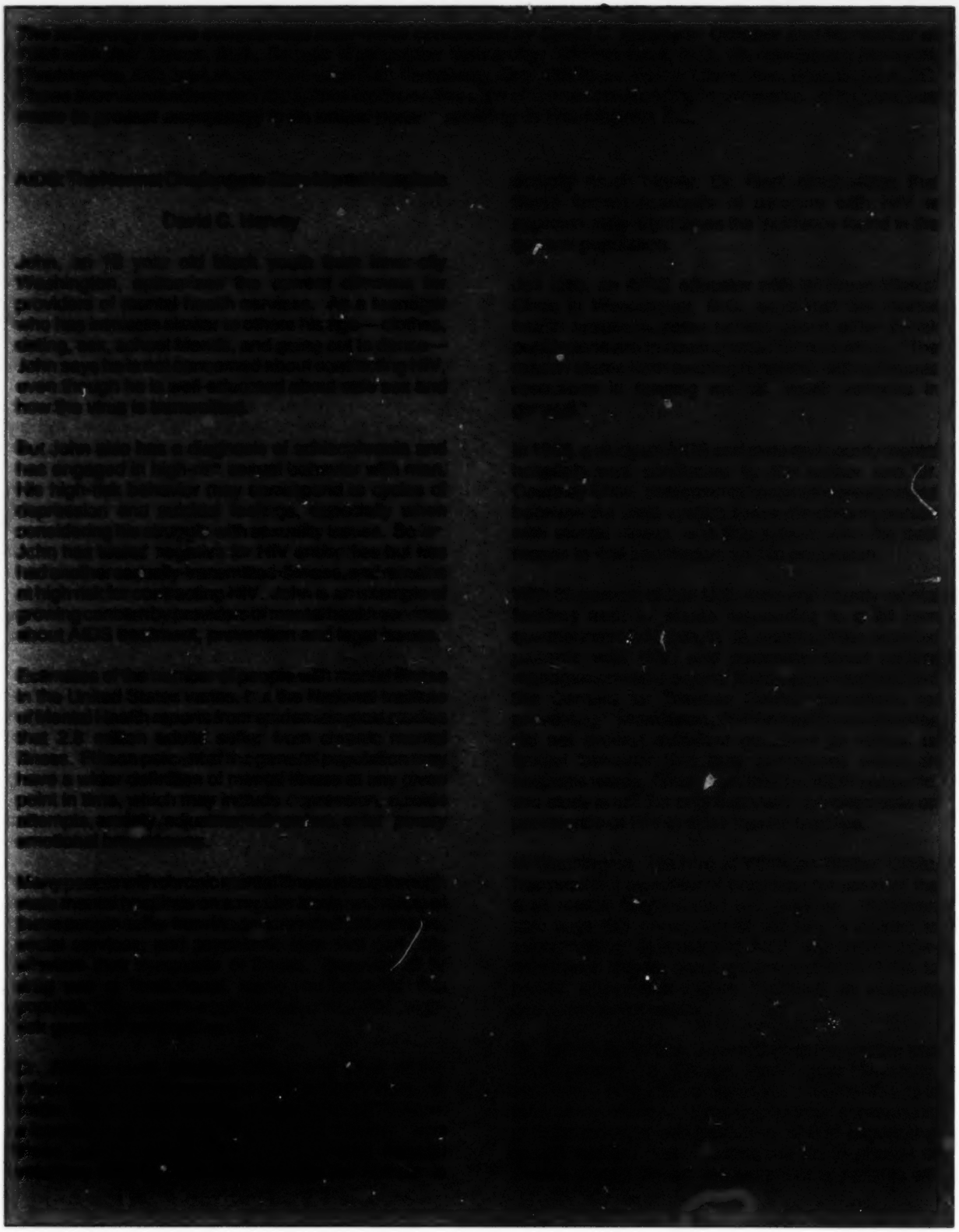


frequently be impaired. Persons who have schizophrenia, a serious brain disease, may have difficulties planning ahead regarding complex issues including safer sex practices to avoid transmission of HIV and other communicable diseases," Aronson says. In addition, persons who have bipolar or mood disorders may experience periods of impaired behavior with increased sexual activity, thereby potentially placing these persons at increased risk for contracting HIV.

Professionals working with persons who have serious mental illness must be educated about HIV disease and its prevention and must be knowledgeable about serious mental illness and accompanying behavior. Often, it is not until HIV is actually present on an ill-patient's psychiatric unit that a facility will actually begin to cope with the disease. Dr. Aronson recommends that hospitals must have written policies on admission of patients and staff, infection control procedures with access to accompanying safety equipment, testing guidelines and informed consent before they are faced with a problem and most importantly, "staff must implement these practices on a daily basis."

During an interview with Dr. Gant at St. Elizabeth's, however, he emphasizes how patient attitudes and behavior differ when educated about health, and when treated with respect. "At John Howard Pavilion, we are making tremendous efforts to bring patient care up to high standards, which includes coping with HIV."

Legal issues involving HIV in the general community have caused Americas to reassess public health measures, to criminalize the intentional transmission of HIV in some states, and to call for anti-discrimination legislation for people with HIV. People with HIV have experienced wide-ranging discrimination and social stigma in securing housing, social and medical services, maintaining jobs, or losing medical insurance. These issues are not new to people with mental illness who have experienced the same discrimination and stigma, but those who also have HIV suffer from double stigma.

Because state mental hospitals are primarily funded and regulated by individual states, the state has a responsibility for ensuring a safe environment, free from risk of contracting deadly diseases. The state's responsibility for preventing HIV transmission, specifically on legal grounds, however, is unclear because of the complex nature of HIV. This includes transmission through consensual sexual behavior of clients, or difficulty in proving negligent transmission between staff or clients. In addition to concerns about liability issues, the conflicts between confidentiality, governed by laws and professional ethics, and a possible legal duty to warn others of a patient's [illegible] HIV [illegible] medical, social and other support services, are evident. Perhaps most controversial are issues regarding [illegible] of persons with HIV, mandatory HIV testing, and obtaining informed consent for testing.

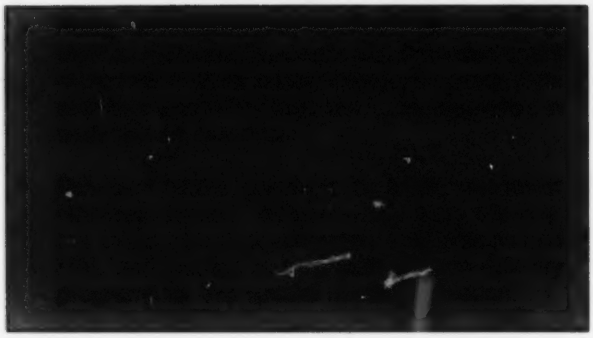
Dr. Rost states that HIV testing should be a part of routine medical testing completed with patients upon admission so that treatment can be accurate. He says, "patients need to know so that they will change their behavior and not infect others."

Other advocates disagree and say that Constitutional issues are present regarding the legality of testing, and because of the risks of discrimination, stigma and service denial, especially regarding persons who have mental illness, issues of infection control, prevention, and treatment can be handled through other means. This can include voluntary testing, counseling, health assessments of high-risk behavior, and medical referrals and follow-up.

Research also indicates that knowledge of one's serostatus does not necessarily change behavior, which may be especially true for persons with mental illness whose judgement may intermittently be impaired. Some mental health experts also fear that mandatory testing may drive patients who suspect they are infected underground, and hence, leave the service system where minimal health care, counseling about prevention, and health education could be provided.

However, a more crucial problem revealed by examining how state mental hospitals are coping with patients who have HIV infection, is how HIV demonstrates existing inadequacies in the system of mental health care in this country. The number of homeless persons with mental illness, staffing shortages in mental hospitals, poor or nonexistent medical services for persons with mental illness, lack of community services, and the rate of abuse and neglect in mental hospitals are merely a few examples of the deplorable state of the mental health system.

One of the few lawsuits dealing with HIV and psychiatric care highlights our problems. A young women with AIDS undertook a major lawsuit against Howard University Hospital for failure to admit her into its psychiatric unit. The case was settled out of court but did dramatize an important issue. Howard University Hospital had a written



Harvey and Elliott (1990) found that AIDS education training in state mental hospitals appears to have been provided to a wide-range of staff; however, it also appeared that hospitals have either conducted education programs only once or covered the issues in the context of other sessions. This has great bearing on programs for patients, since in most cases, staff will educate patients.

Recommendations for Policy

1. AIDS education programs must be instituted on a regular basis for staff and patients.

2. Primary education programs should concentrate on prevention, safe sex, use of condoms, sexuality, and other health issues.

3. Secondary education programs for persons already infected should include information on safe sex, disclosure of health status, access to services, and other issues.

4. The audience must be assessed by age, culture, educational level, cognitive and emotional development, and diagnosis.

5. Institutional policy must be considered in educational programs while maintaining the integrity of HIV prevention efforts.

6. Resources should be secured to provide these educational programs from the state.

HIV Testing

States have jurisdiction over financing, managing and regulating state mental institutions, and subsequently, HIV testing policy is a state issue. However, state laws differ on mandatory, routine and voluntary HIV testing of persons in institutions. Many States, as reported by the Intergovernmental Health Policy Project (IHPP) at George Washington University (1989), are currently considering legislation aimed at instituting mandatory HIV testing in mental institutions.

Currently, Missouri, Texas and Wisconsin have instituted mandatory HIV testing of patients in mental hospitals. Missouri authorizes testing without consent of participants in methadone treatment programs for IV drug users, or any patient who is cared for and treated but has refused testing, or if there is reasonable belief that the person poses a risk to others. Texas conducts testing of patient's whose medical or social management would change if HIV status were known, or patients undergoing invasive medical procedures that could expose health care workers (Intergovernmental Health Policy Project, 1989).

In addition, the Policy Project also reports (November 1989) that seven other states have laws governing mandatory or authorized HIV testing of persons deemed incompetent, and include: Connecticut, Delaware, Georgia, Hawaii, Idaho, Rhode Island and Washington. Fourteen other states have laws on testing patients in emergency situations and include: Florida, Illinois, Indiana, Iowa, Louisiana, Maine, Michigan, Nebraska, New Mexico, North Carolina, North Dakota, Ohio, Utah and West Virginia.

Results of the study by Harvey & Elliott (1990) indicate that while voluntary testing is widespread among mental hospitals, only a few administer tests routinely upon admission. More than a fourth of hospitals responding to the survey conduct some form of mandatory testing or target specific groups of patients for testing such as IV drug users, and those who exhibit high-risk behavior.

Issues regarding mandatory HIV testing without informed consent are largely unresolved in state courts. Some states, as mentioned above, are considering specific legislation on this issue while others are relying on past procedures. In some cases, Section 504 of the Rehabilitation Act is being used to resist mandatory testing, and mandatory testing may also raise Constitutional issues of lawful bodily "search" under the Fourth Amendment to the U.S. Constitution, as well as other relevant laws.

Some policy-makers argue that mandatory testing may minimize claims of liability because identifying and giving special treatment to those with HIV will reduce chances of negligent exposure. In addition, identifying patients with HIV allows early drug therapies and treatment to be administered, and that patients need to know their status in order to change high-risk behavior.

Opponents argue that there is no proof that knowledge of one's HIV status alters high-risk behavior; that testing and re-testing is cost prohibitive; that identifying patients with asymptomatic HIV infection is unethical if access to health care and drug therapies cannot be guaranteed.

Recommendations

1. HIV testing policy should consider state laws and regulations regarding informed consent.

2. Options for testing policy should be formed after consultation of guidelines from the Centers for Disease Control and other federal agencies.

3. HIV testing policy should not be used as a means towards general infection control policy, towards restricting or isolating patients identifed with HIV, or to deny access to services. Clients should be treated by clinical behavior and not HIV status.

4. As technology, drug therapies and medical treatment evolve, HIV testing policies should be re-examined.

5. A institutional professional advisory committee, represented by physicians, social workers, disability attorneys, and administrators should draft guidelines on testing.

Confidentiality

Traditional public health measures and provisions that allow for protection of civil rights are based on principles of confidentiality. However, balancing the rights of persons with HIV with the duty to warn third parties is a central dilemma for policy makers in institutions.

Laws, professional code of ethics, and regulations governing institutions maintain the confidentiality of medical records. Breaches of confidentiality have led to discrimination in housing, services and employment.

With the need to place information about HIV status in case records, there has been increased concerns about how to maintain confidentiality. People with mental illness already experience stigma and discrimination, and may suffer from a double stigma from persons knowing their HIV status.

The Intergovernmental Health Policy Project (1989) reports that 30 states have enacted confidentiality laws related to HIV test results, and eight states have strengthened confidentiality provisions in existing communicable disease laws.

Recommendations

1. Institutions should have procedures in place for noting information about HIV in patient charts in a confidential manner.

2. Confidentiality should be protected by penalties for breaches. Only those staff persons have a direct need to know should be informed of HIV status.

3. Confidentiality procedures should be consistent with state laws, state regulations, and professional code of ethics.

4. A professional advisory committee made up of cross discipline staff should review confidentiality procedures.

Duty to Protect

Duty to Provide a Safe Environment

In 1982, a case involving an involuntarily committed adult with mental retardation who suffered injuries in a Pennsylvania state institution, Youngberg v. Romeo (1982), was decided by the Supreme Court. The decision involved a duty of the state to care for and protect individuals within state custody under the Fourteenth Amendment to the U.S. Constitution. Individuals with mental retardation, voluntarily or involuntarily committed to a state institution, have a constitutional right to live in reasonably safe conditions, and be free of undue bodily restraints within that institution.

Other courts have interpreted the Fourteenth Amendment as guaranteeing the right to safe conditions in institutions as encompassing adequate food, clothing, shelter, medical care, dental care, and supervision, as well as protection from dangerous situations, such as slippery floors, crowding, harmful noise levels, and safety from attack from others (Society v. Cuomo, 1984). Since mental illness can affect judgment and the ability to protect oneself, providers may have an obligation under the Fourteenth Amendment to protect clients from the transmission of the HIV virus from or to other clients (Rennert, 1989). Duty to protect may also require sex education programs in order to minimize transmission through altering high-risk behavior.

Confidentiality & Duty to Protect

Although the law requires disability service providers to protect the confidentiality of their client or patient's medical information, disability service providers may have a competing obligation to protect or warn a third party from harm, and failure to do so could bring liability for negligence. A client or worker of an agency or institution could recover damages for negligence if the breach of duty directly and proximately (closely related in time, space, or order) causes an injury resulting in actual damage.

A physician has a duty to protect third parties from physical harm by warning specific individuals at risk that the patient has a contagious disease, if, according to the 1965, Restatement (Second) of Torts (Wright, 1944) (a "restatement" is a generally accepted explication of the law and often persuasive to courts):

> (a) a special relation exists between the actor and the third person which imposes a duty upon the actor to control the third person's conduct, or (b) a special relation exists between the actor and the other which gives to the other a right to protection.

In addition, some states permit disclosure of information by physicians under certain circumstances (Rennert, 1989).

More specifically, as a result of Tarasoff v. Regents of the University of California (1976), the California Supreme Court imposed a duty to warn on psychotherapists in order to protect third persons from potentially dangerous acts of clients. This doctrine has been adopted in New Jersey, Nebraska, and Vermont. This is further clarified in U.S. v. Louis Markus (1984) when:

1. The third person is a foreseeable victim or within a class of foreseeable victims.

2. The defendant has knowledge of a specific danger to the victim.

3. The defendant possesses special skills which would enable it to recognize the danger.

4. The defendant stands in some professional relationship to the dangerous person or condition which arises from defendant's special skills.

5. The defendant has some measure of control over the dangerous person or condition, which the defendant in his professional capacity could exercise to prevent the harm.

Accordingly, the law in some jurisdictions, imposes obligations on physicians and therapists because of their unique position, due to their training, experience, and relationship with their patients, to foresee harm to third persons and to take steps to prevent harm. The physician or therapist does not need to have a personal relationship with the third party who could be hurt.

Generally, the physician's or therapist's duty to protect others is limited to identifiable victims - persons known to be at risk of injury. There is no duty to protect the general public; a physician's or therapist's duty to protect others may be triggered when the patient poses a serious risk of danger to specific persons (Rennert, 1989).

Whether a similar legal duty could be imposed on other types of professionals - educators, social workers, attorneys, counselors -remains unclear. It is not clear that a teacher or attorney would be considered to have the same type of relationship, or extent of knowledge, as a physician. As to social workers or counselors, the duty may be extended, as they share the same unique relationship as those more broadly designated as psychotherapists, where clients may disclose specific and detailed information.

This area of the law remains controversial and advocates fear that agencies and their consulting physicians will take actions that breach confidentiality in response to fears of liability and possible harm to third parties. This breach should only be considered in extreme circumstances after all other options are employed. Breaches of confidentiality and warning of third parties may need to be considered by a Judge in a court of law before any actions are undertaken.

Recommendations

1. Institutions and advocates should consult with disability attorneys, local departments of public health, and medical counsel regarding any duty to protect.

2. Institutions should have in place specific procedures for interventions when there is question of a duty to protect.

3. Staff should always consult with the patient first and request voluntary cooperation of patient.

4. All actions and patient information should be documented in records according to procedures established to maintain confidentiality.

Tort Liability for HIV Transmission

In the current climate, mental health institutional administrators and staff are concerned about how to minimize possible findings of liability from worker or client exposure to HIV infection. The central dilemma is how to avoid liability and balance the duty to protect others from harm, while protecting individual civil rights. For example, there is concern about institutional responsibility to prevent HIV exposure through consensual sexual behavior between two clients. Other concerns center on worker exposure from clients or vice-versa. The courts and legislatures are begining to define key issues related to HIV transmission.

Specifically, general principles of law will be applied to claims of liability that might be brought against an agency or facility on claims of negligent transmission between clients or workers in the following situations: (1) a failure to provide a safe environment; (2) negligent worker exposure; (3) failure to maintain confidentiality; and (4) failure to protect or warn.

Findings of liability may be minimized when agencies and facilities institute state-of-the-art policies such as universal precautions and infection control procedures, as defined by the U.S. Centers For Disease Control, U.S. Occupational Safety & Health Administration, and other sources, and agencies have in place policies regarding consensual sexual behavior between clients with procedures for intervention in high-risk situations.

To minimize findings of liability for negligent exposure of clients or workers to HIV in mental health services, and policies to protect the civil rights of clients should include the following protective actions: (1) infection control policy and procedures for implementation; (2) sexual behavior policy and procedures for counseling and intervening with clients who are recalcitrant; (3) record keeping policy and procedures on confidentiality; (4) HIV testing policy and informed consent procedures; and (5) creation of a professional advisory committee with multi-disciplinary members that include disability attorneys, physicians, social workers, other experts, etc. to advise on policy development and ongoing issues.

Recommendations

1. Institutional staff and advocates should consult publications on infection control policy that among others includes: the U.S. Centers for Disease Control on "Recommendations for Prevention of HIV Transmission in Health-Care Settings" (1989); 2) U.S. Department of Labor and Department of Health & Human Services (OSHA) notices, "Protection Against Occupational Exposure to

Hepatitis B Virus (HBV) and Human Immunodeficiency Virus (HIV)" (1989), the "Joint Advisory Notice" published by DHHS and the Department of Labor (1987); and, 3) other publications on infection control policy.

2. Individual legal counsel should be sought by each agency or facility, or consultations should be sought with Protection & Advocacy legal services.

3. Individual expert medical counsel should be retained by each agency or facility.

4. Policy should be developed on high-risk situations involving clients or staff within facilities.

5. Management of recalcitrant behavior by clients should be defined, together with procedures to deal with noncompliance with standards by employees that include removal from employment if standards are breached.

6. Keep detailed records that document all activities with staff and clients on administrative procedures, training and education, work practices, personal protective equipment, and record keeping.

Access to Services

Ironically, the service system that is in place to serve persons with mental illness, in some cases, is denying services to persons with HIV for a variety of reasons. This includes lack of understanding about the basic clinical course of the disease, fear of program liability, lack of adequate education of clients and their families, and the extreme burden placed on already inadequate resources. Many state institutional mental health systems have patients with HIV in their wards and may not be aware of this fact.

Clearly, the mental health system will increasingly see patients with HIV. In most cases, there will be no other service systems to refer these clients to and the mental health hospital will be forced to provide services to these patients.

Many people with HIV disease have experienced trouble in securing and paying for medical care and expenses. Many of these people lose or have no private health insurance. These persons experience eligibility requirement problems with Medicare and Medicaid that include waiting periods that may outlast their health, requirement of a definitive diagnosis of AIDS excluding less serious HIV conditions, or may be above the income and assets eligibility, but are also disabled and unable to work.

These issues are not new to persons with chronic mental illness who may already be qualified for benefits under Supplemental Security Income (SSI) and Supplemental Security Disability Income (SSDI) programs, with accompanying Medicare and Medicaid health care support services. However, obtaining quality and readily available medical care and other services for persons with disabilities has traditionally been an issue, especially with the onset of deinstitutionalization and increasing competition for resources between institutions and community providers. HIV disease further complicates these problems.

Physicians and other service and medical treatment professionals are ethically bound to provide treatment to persons with mental illness and HIV. The American Medical Association and the American Bar Association's AIDS Coordinating Committee (1988) states:

> Professional ethical obligations may become legally enforceable obligations if they constitute the standard of care against which professional regulatory boards or juries deciding malpractice claims measure a provider's conduct (p. 72).

Mental health institutions face challenges in guaranteeing access to patients who need expensive drug therapies to treat HIV related illnesses, and other medical and social services. An increasing challenge will be to meet the complex medical, social and physical needs of these patients.

Recommendations

1. Access to needed medical and social services should be secured by institutions.

2. If resources do not exist for adequate services, referrals should be made to other social service or medical clinics to provide medical care. This may require establishing referral procedures or establishing relationships with AIDS service organizations.

3. Patients should have access to the latest developments in drug therapies and treatment.

4. Institutions and advocates should ensure that patients with HIV are not denied access to community mental health programs.

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